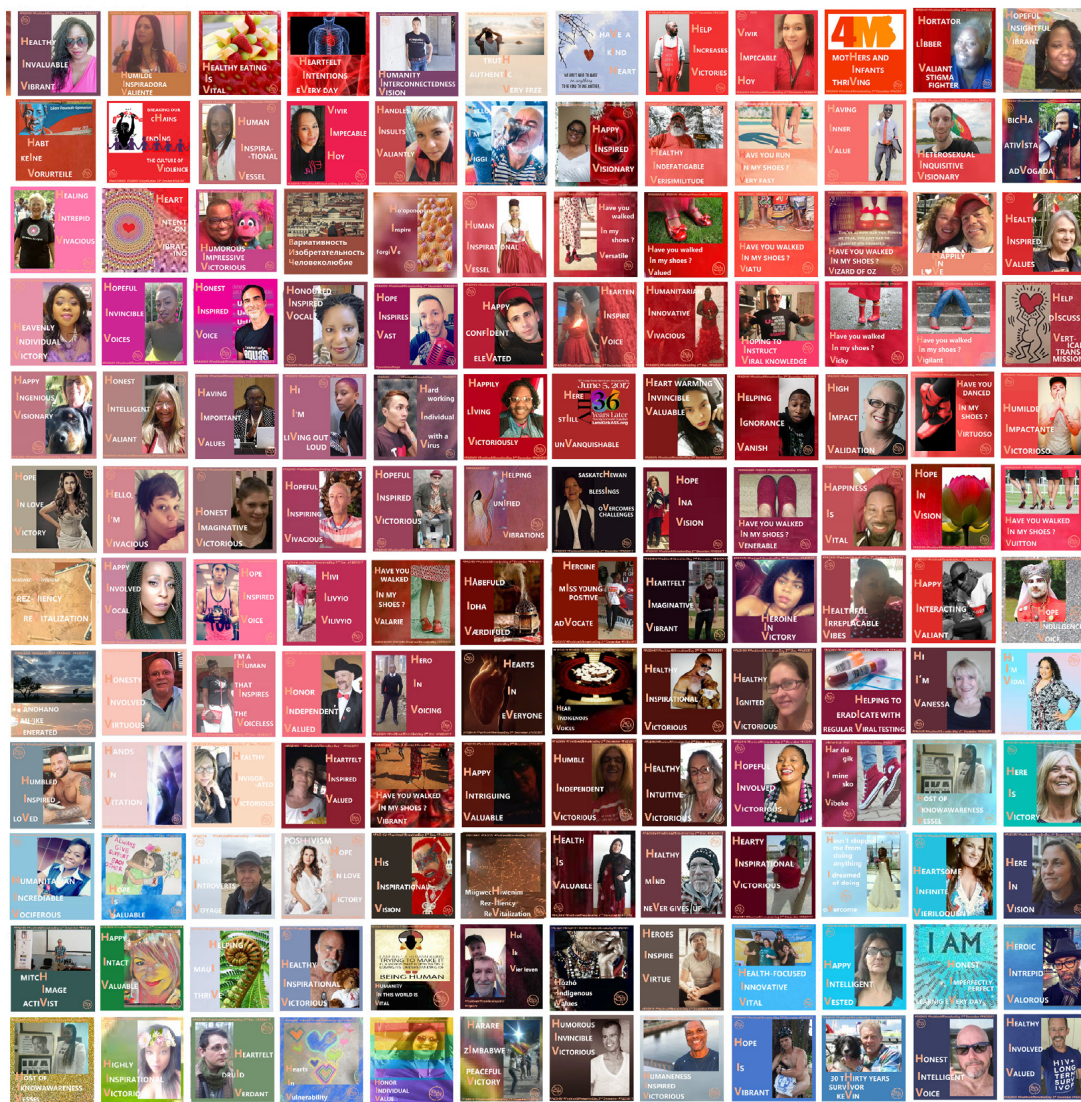


# TEN YEARS AFTER



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A special thank you to UEL Graphic Design (BA hons) Hannah Coles, Sneha Modhvadiya and Patrick Mayhew for designing this report.

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# Ten years after: An 'austerity audit' of services and living conditions for people living with HIV in the UK, a decade after the financial crisis.

HIV Psychosocial Network

## Preface

Nowadays it is hard to recall the fear, panic and despair that gripped the world as the HIV/AIDS epidemic ploughed through the lives of individuals, families, communities and entire nations.

The epidemic cut a swathe through communities and often those affected were the youngest and those who carried the hopes and aspirations of their families and communities.

In the last 30 years much progress has been made in developing new treatments and making them accessible to tens of millions of people across the world. We must also celebrate declining new HIV cases in many places - the 28% decline in HIV diagnoses in London over the past two years, for instance.

Where we are now was almost inconceivable twenty years ago and unimaginable years before then.

So much effort, time, dedication and co-operation has gone into these efforts and the collaboration amongst people living with HIV, activists, medics, healthcare

workers and policy makers has shifted, probably forever, the ways in which health care is perceived and delivered. The UK voluntary sector has been central to shaping health and social policies with regard to the needs of people living with HIV in addition to providing targeted services that underpinned the amazing advances in HIV care over the past 20 years.

However, the policies of austerity threaten these amazing advances. Despite the availability of effective antiretroviral medication, the difficulties associated with living with HIV have not gone away. We know that people living with HIV have higher rates of mental health difficulties than the general population, that late HIV diagnosis and poorer health outcomes remain a problem. The small print in contemporary optimistic figures around new diagnoses reveals those who are left behind: BAME communities. HIV stigma remains a real problem for many people. HIV is probably still one of the most stigmatising conditions in the world and is exacerbated by social conditions that are completely solvable. Alongside second-to-none advances in biomedical achievements, we have simultaneously seen

a 100% increase in people needing food and shelter, having their welfare claims rejected, decreased support with immigration cases, challenges to people with HIV's general living standard and a general downturn in funding.

This report highlights needs beyond the biomedical model, clearly defines the actions that must be taken and sets a research agenda to bring our learning and thinking about psychosocial issues into harmony with the biomedical advances that we've made around HIV.

We are not claiming that the impact of austerity has not hurt others with long-term medical conditions, nor that people with HIV deserve special or privileged treatment. However, the issue that distinguishes HIV from other diseases is the stigma attached to it. Through the process of stigma peoples' humanity is stripped away facilitating discrimination and injustice.

When services to people with HIV cease, reduce or are withdrawn the process of HIV stigma becomes even more entrenched. We know that stigma underpins poorer mental health, poorer self-care and poorer adherence to HIV medication. The voluntary sector have previously been able to offer tailored and specialised services to people with HIV that enabled them to live their lives to the fullest. Austerity policies have reduced core funding that has meant that many voluntary agencies are no longer able to provide the services they once did. Indeed, many agencies have simply closed.

This report is the first to examine the impact that austerity policies has had on the ability of the sector to deliver services. Unsurprisingly, the effects have been profoundly negative. However, this report also points to the resilience of some agencies and services that speaks to the energy, commitment and passion of this sector.

This report deserves careful reading and reminds us that the politics of austerity has many unintended consequences.

*Deborah Gold, Chief Executive, National AIDS Trust*

*Marion Wadibia, CEO, Naz Project London*

*Chris Woolls, Director, River House*

# Summary



Shan Kelley, *Self Portrait*, 2013. Image used by kind permission of Shan Kelley, <https://shankelley.com/>

*We are seeing more (people with HIV) falling below the poverty line, needing food vouchers or parcels. Many people's benefits get interrupted and this can cause distress and anxiety. (Survey respondent).*

*I joined my organization in 2010 and every year has been a challenge in terms of reductions in funding, funders not wanting to fund HIV services and statutory funders expecting the same for far less. (Survey respondent).*

<sup>1</sup> **Enormous progress has been made in tackling the HIV epidemic.** Many people with HIV are leading healthy and happy lives, with fulfilling relationships and work. **Yet problems remain.** Significant numbers of people with HIV have health difficulties, those from less powerful communities may be 'left behind', and psychosocial issues related to HIV remain under-addressed. In addition, since 2008, the financial

crisis and accompanying UK 'austerity' policies have generated cuts in health and especially social services that have severely affected HIV services and the lives of those living with the virus.

<sup>2</sup> The HIV Psychosocial Network, an association of organisations, interested individuals, and academics, has conducted an **HIV Austerity Audit** to determine the effects of the past decade of austerity on the HIV sector and the lives of people with HIV. The project included a survey of Network members and associates, and an analysis of documents and webpages of member organisations. It was supported by the University of East London's Civic Engagement programme, as well as by all member organisations.

## **Key findings include:**

- **Overall funding loss and service cuts**, in both medical and social fields.
- **A newly 'hostile' environment around benefits**, creating problems for service providers and negative psychosocial effects for many people with HIV.
- **Increased economic and social exclusion** due to: rising destitution; problems of unemployment or over-stressful employment; insufficient wages or benefits; food, housing and transport insecurity; and disrupted social support.
- **Insufficient attention to complex intersectional issues** that affect many people with HIV, around ageing, living



long-term with HIV and anti-retroviral therapy, complex health problems, sexualities, gender, violence against women, racism, children, citizenship, drug use, poverty, and urban-rural divides, all of which may intensify people with HIVs' marginalisation.

- A negative '**cascade effect**', resulting from cuts that reduce safety nets for the most psychologically and socioeconomically vulnerable people with HIV.

- **Continuing stigma and discrimination** for some.

- **Declines in supportive 'HIV community'.**

- **Persistent mental health issues affecting significant numbers of people with HIV, exacerbated by austerity** and particularly strong for people already dealing with other issues, leading to greater mental health demands on service providers.

- **Many people with HIV who claim benefits experiencing intense shame.**

- **HIV organisations closing, or spending large fractions of their time finding new strategies** to continue their work with lower budgets.

- **HIV organisations continuing, despite budget cuts, to provide existing services and to develop new services**, particularly to cover service users' increased socioeconomic needs, cuts in benefits, new issues and groups within the epidemic, and continuing needs for face to face support and support continuity.

- **Limitations of voluntary sector and informal support** covering up gaps in statutory provision.

- **Continued high effectiveness of HIV organisations, accompanied by repeated warnings that they are at**

**breaking point.**

- **Strongly detrimental effects of sustained cuts in health and social service funding and services on the psychosocial wellbeing of many people living with HIV in the UK.**

- **Requirements for integrated and HIV-specific health and social service provision, as well as appropriate levels of funding**, in order to meet the promise of medical advances against HIV.

# 1. Introduction: Living with HIV in the UK today

Immense progress has been made in tackling the HIV epidemic. This is demonstrated in the UNAIDS' <sup>1</sup> 90-90-90 targets for 2020 - 90% of people with HIV to know their status, 90% of people with HIV to be on antiretroviral treatment, and treatment to reduce viral load to undetectable in 90% of cases. By 2030, the aim is to end HIV as a public health threat.

UNAIDS warns, however, that there are 'miles to go' <sup>2</sup>. Groups most likely to be HIV positive or affected - gay men, young women, and intravenous drug users - and those who are least powerful, like children, young women, people with disabilities, and the poor, are being 'left behind'.

In the UK, the 90-90-90 targets are nearly met, and there are decreasing new diagnoses and HIV-related deaths. Most people with HIV get highly effective medical care, including immediate antiretroviral treatment, and have excellent experiences of it. For 94%, viral load is undetectable and this means they cannot transmit HIV. People with HIV mostly live with good mental and physical health, for a normal life and lifespan, without AIDS-related illness. They engage in satisfying work and fulfilling relationships, and have good support from those around them, particularly HIV psychosocial services. UK HIV diagnoses are falling dramatically among gay and bisexual men and other men who have sex with men, and late diagnoses are decreasing among most groups, because of increased testing, immediate



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Living with HIV may also still be problematic. For many, HIV, like other chronic illnesses, is a difficult condition. Treatment, while overwhelmingly successful medically, can still present some physical as well as mental and socioeconomic problems. As a result of continuing stigma, people with HIVs' work, social and personal relationships can be affected. Many people with

A frequent theme of all our Network discussions has been how austerity has created high levels of economic hardship, social exclusion, and psychological distress. These ‘austerity effects’ appear regularly in Network



organisations' own reports. However, much of such community-based research only addresses specific policy changes or client groups, analyses just its own initiatives, and has relatively small audiences. In addition, similar academic and larger-scale policy research has also mostly focused on specific client groups or service cuts.

The Network therefore decided to conduct an 'austerity audit', to bring together and update Network member organisations' research findings about the effects of a decade of austerity on HIV services, and on the lives of many people with HIV.

The HIV Psychosocial Network began in 2015 and includes around 40 small and large HIV organisations, interested individuals, and academics. Our aim is to discuss, develop and take forward HIV research in the field of psychological and social conditions and care, from the perspective of people with HIV and organisations working with them.

<http://hivpsychosocialnetworkuk.tumblr.com/>

## 2. Auditing austerity: Conducting the research

The aim of this study was to gain an overview of austerity's effects on HIV services and living with HIV by:

- a) conducting a survey of Network members and associates and
- b) analysing Network organisations' existing reports on austerity's effects.

This work was conducted at Network meetings, and by email communication between interested Network members, between summer 2017 and 2018. <sup>6</sup>

**The austerity survey:** Network members developed a brief survey which was distributed to the Network and associates in summer 2017. The study received ethical approval from the University of East London ethics board. Survey questions resembled those used in earlier research and reports, addressing social, psychological and health changes among service users since 2010, organisational challenges since 2010, current key issues for service users, and additional points. Information about the respondents and their organisations was also collected (Appendix 1).

There were 25 respondents, with 64% (16) completing all questions, and 36% (9) completing some questions. Five respondents described their organisation as a national organisation, eight as a regional/county organisation, and six as a local organisation, with six respondents not specifying. Eleven respondent

organisations said they helped all people with HIV, four helped anyone HIV-affected; three organisations reported more specific client groups. Three-quarters supported under 1000 service users; the remainder supporting more than 1000 service users. Fifteen respondents had been working in the sector for more than six years. (See Appendix 1).

**b) The austerity reports:** We circulated a call for publically available reports and other materials such as newsletters and websites to Network members and associates in late 2017. Of those submitted, academic research papers, summaries of others' research, or documents with mainly non-HIV concerns, were not analysed. We also sampled across organisations and document types from among those submitted, rather than including high numbers of reports from larger organisations. This process gave us 32 documents from 20 organisations (See Appendix 2). The spread of organisations represented roughly paralleled those from which survey respondents came in terms of their size and client type.

Responses to Network emails about the research exemplified the challenges within the sector. A number indicated that a number of organisations had lost funding, merged, or closed.

**c) Analysing the austerity data:** Survey responses were used to develop a coding frame, using thematic analysis, which was then checked with the reports,

modified, and applied to both datasets. Psychosocial concerns - that is, those where social and individual factors interrelate, including in connection with medical issues - were given particular attention, in accordance with the Network's interest in psychosocial requirements and service provision around HIV. In what follows, we look at broad analytic categories which we developed from the smaller themes <sup>7</sup>.

struggling, and that their challenges need continued attention and action. Their needs are what motivated this research <sup>8</sup>.



*Images used by kind permission of Sanny Mulubale*

We recognise that this research is limited. Most importantly, it draws largely on services for and experiences of people with HIV who have physical, mental and/or socioeconomic challenges. Yet large numbers of people with HIV are living well, happily and successfully. This group is not well represented in our research. At the same time, many people with HIV are

### 3. Cuts and restructuring: the 'hostile environment' in health and social services

*Key issue: The reduction in HIV support services. The lack of awareness and understanding that HIV+ people continue to need support regardless of the fact people now have a much greater chance of living a relatively normal life and lifespan. The stigma is still there and makes living with HIV an everyday challenge for many people. (Survey respondent).*

Austerity has been assessed as having detrimental effects on health throughout Europe <sup>9</sup>. The increasingly negative effects on the lives of people with HIV was a major theme, occurring in all documents and most survey responses. These effects appeared particularly strongly in the anonymised surveys. Firstly, 13 respondents, asked about recent changes, gave often highly detailed accounts of **funding loss and service decline**.

*Changes across the social care, public health and legal sectors - seems to have led to some fragmentation and lack of continuity of care for clients. Also, we have annual contract reviews (often last minute) which made it very difficult to do any forward / business planning. (Survey respondent).*

*Staff and service reductions and interruptions due to funding climate. Closure of many partner services in the city e.g. a satellite welfare rights clinic held in-house until 2013 for LGBTQI service users. Loss of well-established complementary therapy service provision.*

*Reduction of counsellors and counselling time/hours available. (Survey respondent).*

Second, the data indicated frequent experiences of **HIV treatment cost constraints**, and **reductions in other medical services**, especially mental health and GP provision.

*Medication changes to cheaper generics causing upset and fear of treatment failure. (Survey respondent).*

*People are having difficulty getting GP appointments due to pressure on GP services. (Survey respondent).*



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Third, many people with HIVs' **reduced access to income, food, housing, transport, and psychosocial support** because of statutory and voluntary sector cuts, were consistently noted. We will expand on these issues in later sections.



*Many are facing uncertainty as benefit changes take effect, some are losing a major part of their income and [there is] a resulting loss of independence. (Survey respondent)*

Fourth, the **'hostile environment' around benefits** was itself having detrimental psychosocial effects for some. Assessments were uncertain, time-consuming, exhausting and distressing, especially when appeal was required; HIV organisations were over-stretched. Many financial problems resulted:

*The level of stress, anxiety and confusion as a result of welfare changes has increased considerably. Poverty goes hand in hand with these psychological issues. (Survey respondent).*

Assessments tended to treat mental health, mobility, home care, and complex needs too narrowly; and difficulties multiplied for those facing other issues – for instance, asylum-seekers:

*People who are waiting in the asylum system often have a really hard time. The waiting is so dehumanising. The system just doesn't work. (Terrence Higgins Trust, 2017, p25).*

Often, the system seemed actively to oppose clients:

*Case Study 4: ... The client had a lot of relevant evidence from his clinical team. He ... reported to his support worker that 'they did not hear everything he had to say'. (National AIDS Trust 2017b, p1).*

Stigmatising hostility in the media towards benefits claimants was thought to have harmed many people with HIVs' views of themselves:

*'Scrounger' narratives in the media have affected many clients - some now will not apply for PIP (Personal Independence Payment) despite being entitled - especially if they have a less visible disability e.g. mental health issues, BBVs (blood-borne viruses). (HIV Scotland and Hepatitis Scotland, 2014, p33).*

## 4.

# Economic and social exclusions

*Since working in the sector I've seen increased levels of poverty. We give more food bank vouchers than before. Clients moved into Universal Credits go into economical hardship because delays in payments. Increment in clients at risk of losing their home.*  
(Survey respondent).

HIV organisations and researchers have been warning of the growing effects of poverty and consequent social exclusion among people with HIV since the mid-2000s<sup>10</sup>. In our data, both organisation documents and survey responses described economic and social exclusions as increasing, and as generating rising destitution:

*[We're] supporting people living in absolute poverty.*  
(Survey respondent).

Survey respondents and organisations alike recognised the **problematic employment situation** for many people with HIV, especially for those with poor or fluctuating health, and in a benefits situation pressurising them towards low-waged and often health-compromising work:

*Getting and keeping a job is not always easy. ...Unfortunately, despite the 2010 Equality Act which bans discrimination on the grounds of health, applicants' HIV status continues to be linked to their dismissal or continued unemployment. Losing a job is stressful and the uncertainty and delay around benefits*

*payments makes it harder.* (Terrence Higgins Trust 2017, p15).

Survey respondents especially noted how the benefits changes associated with austerity have led to many more clients presenting with **financial needs**:

*Things have become much tougher, particularly for those with no recourse to public funds. There has been an exponential increase in the call on our Hardship Fund.* (Survey respondent).

The most direct effect of increased poverty and benefits changes was on food security. Documents and respondents presented the issues as interlinked:

*There has...been a greater demand for the crisis payments and the small food parcels that we give out and Sahir House has for the first time become a referral agent for local food banks.* (Sahir House 2012-13, p.7).



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Poverty, exacerbated by austerity, accompanied by housing shortages and problematic new housing policies and reduced housing benefits, was also producing severe **housing problems** for some people with HIV:

*There is much more destitution, homelessness.*  
(Survey respondent).



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**Transport poverty**, interacting with other benefits restrictions, was restricting many people's nutrition, exercise, and sociality:

*There is a mood of despondency causing people to make lifestyle choices that in a mood of optimism and hope would be different e.g. more nourishing and sustaining choices. Choosing to not go out due*

*to pressure on finances around travel expenses, gym memberships that once could be explored are very limited and healthier fresh food choices (usually more expensive) restricted due to decrease or interruption of benefit support.* (Survey respondent).

More generally, economic austerity was intensifying **social disruption**, as many people with HIV, especially those relying on statutory and voluntary psychosocial services, found they could no longer access the support they needed:

*Quite radical changes to social welfare system seem to have led to...less home care for our service users.*  
(Survey respondent).

*Many clients are returning to employment/ training and the need for [ cut] support services outside of working hours has increased.* (Survey respondent).



# 5. Complex needs, multiple marginalisations

*Key issue: We work mainly with older people, people living long-term with HIV or late diagnoses so we have a vulnerable cohort. Our clients tell us that they feel like the 'forgotten people' - lack of visibility, continuity of care and constant benefit reviews contribute to heightened anxiety/lack of stability.*

*(Survey respondent).*

As researchers on HIV issues frequently indicate, people with HIV have varying health and other needs. Multiple, 'intersectional' social marginalisations also generate specific requirements <sup>11</sup>.

In this research, ageing was the most-emphasised specific factor. Reports and surveys suggested that as people with HIV aged, they often continued to experience issues with medication adherence and side-effects, while developing, earlier than HIV negative people, conditions like cardiovascular disease. Older people with HIV tended to be poorer, less employed, less well, less mobile, more isolated. Their physical and mental health was more likely to be damaged by cuts in face-to-face services; they dreaded future discriminatory residential care.

*The constant focus on cost cutting and moving services online, removing physical contact, is the last thing an ageing HIV population need. (Survey respondent).*

This cohort seemed to be at the back of the queue. Many surveys and documents called for proper provision for it:

*Effective, co-ordinated, holistic long-term condition management is essential for individuals growing older with HIV who are having to cope with health conditions related to HIV, ageing and the interaction of HIV with the ageing process. (Mildmay, 2016, p7).*



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**Long-diagnosed people with HIV** are often doing well; but some have important specific issues to deal with: long-term HIV illness, and early-generation, long-term treatment:

*Alain's story: What really worries me are consequences on my brain and cognitive functions of living with HIV and taking medication for so many years... Over the last couple of years, everything has started to slow down, like an obsolete computer that is puffing away on its last legs. I exaggerate, but not by much. (River House).*

Many of this group had not expected to survive.



Often, friends and family had died, and they lacked the economic and social capitals of sustained employment.

Despite ill health, some were told to get a job:

*Because some people cashed in their pensions or sold properties so that they might enjoy what they thought would be their final years, there are now associated financial problems. ... People often need help in coming to terms with the fact that they have outlived friends and partners. (DHIVERSE 2017, p.s 2, 7).*

Services for this 'lost generation' of people with HIV have also been cut. The National Long-Term Survivor Group newsletter (2012-2017) documents persistent donation drives to fund attendance at its weekend retreats.

Related specificities were **difficult health conditions**, which affect some people with HIV of all ages and generations. Surveys and documents noted the need for coordinated treatment across increasingly complex physical and mental conditions. Post-2010 cuts were said to have worsened general health and mental distress; new benefits levels and assessments were not appropriate for HIV-related disability.

*[We are seeing] often, more complex presentation. Suppressed immunity, cardiac and kidney complications. We have also seen a higher incidence of mortality recently - for example, two clients died in the past ten days. (Survey respondent).*

*The medical assessments of PIP and ESA (Employment and Support Allowance) are not addressing the barriers, including psychological factors and lack of relevant skills, that impact upon many people with disabilities and long-term conditions, including (people with HIV), when seeking work. (Counterpoint 2014, p3).*

Surveys and documents frequently emphasized the disproportionate difficulties austerity policies caused around **gender, violence against women, racism, children, and citizenship issues:**

*Women from BAME (Black and minority ethnic) communities, Latin Americans and White MSM (Men who have sex with men) over 50 were hit particularly hard by the changes in the welfare reform. (Counterpoint, 2014, p3).*

*People seeking asylum are often relocated losing service continuity and community links. (Survey respondent).*

Welfare reforms were also seen as disproportionately impacting **drug users:**

*42.5% said their financial situation had prevented them from accessing treatment...the impact the reform bill will have on our clients, who are already chaotic, is they will find it difficult to access money from benefits and therefore it will create a worse off population (HIV Scotland and Hepatitis Scotland 2012, ps5, 27).*

Finally, cuts were generating **large service declines outside urban centres:**

*Before 2010 I worked in the sector in London and I found that there was more of a 'HIV community' and therefore more peer support. Working [outside London], there are more issues related to isolation and issues around confidentiality, particularly in a small city. (Survey respondent)*

## 6.

# Stigma, isolation, and loss of HIV community

*Key issue: Although treatment has improved significantly, attitudes to HIV have not. Stigma and fear of discrimination continue to be a huge barrier and burden for those living with HIV. (Survey respondent).*

*Many people living with HIV talk about guilt, embarrassment and shame because of the high levels of stigma associated with this condition. This can adversely affect the levels of support they receive, not only from family and friends but also professional support, and it is often one of the main barriers to people taking an HIV test and receiving an early diagnosis (DHIVERSE, 2017, p.6).*



Shan Kelley, Postcards – i, 2013. Image used by kind permission of Shan Kelley, <https://shankelley.com>

While HIV-related **stigma and discrimination** have reduced for some, UNAIDS suggests they still present significant barriers to prevention, testing and treatment. In this study, stigma – including in medical services- and resultant disclosure fears were key issues for a third

of survey responders, featured in most documents analysed, and were viewed as producing health and psychosocial problems, particularly in already-marginalised communities:

*Lindsay's story: There has been, from the earliest days of HIV, a fear that disclosure of one's status could mean the very worst; physical and mental pain, isolation, the loss of contact with friends and close relatives. This stigma still exists. I can think of no other life threatening condition which is kept secret for fear of the reaction disclosure would cause, and which causes shame and embarrassment. (Eddystone Trust, 2018).*

*Black African refugees and asylum seekers in London are among the most vulnerable to HIV infection... being HIV positive can intensify experiences of stigma and marginalisation, and frequently prevents people from coming forward to access health and social care services. (Rain Trust, 2017, p1).*

Tightened financial constraints, working alongside **stigma**, were said frequently to generate isolation and support deficits:

*People being unable to get to services they need due to their need to prioritise food costs over travel costs...[this] is causing isolation leading to despair and frustration and interruption in peer support. (Survey respondent).*

A commonly noted consequence was **loss of HIV community**, which was described, with many examples, as key for many people with HIVs' wellbeing:

*The first time I visited Body and Soul, I was so scared. I thought that the people there would be visibly sick. How wrong I was! People were smiling, hugging, laughing. It was so different from what I expected HIV to be...From a 12 year old boy who thought he had nothing to live for, I am now living with a purpose and an energy for the future. (Body and Soul, 2014, p2).*

Austerity measures applied to such HIV peer support were noted as widespread, and as increasing isolation even for those otherwise doing well:

*For some clients who are managing their HIV health well and are in employment, we are seeing that some are feeling more isolated as they have little opportunity to meet with other people living with HIV or talk about HIV openly. (Survey respondent).*

# 7. Psychological impacts

*Greater presentation with complex psychological needs and little support outside of our support services due to cuts in services and difficulties accessing specialised appropriate mental health support.*

(Survey respondent).

*Deborah: Things were so bad at one point that I was taking sleeping pills day and night so as not to deal with the issues that were facing me. The support from Brigstowe made me look forward and be positive.*

(Brigstowe Project, 2016, p6).

Research consistently shows that social and economic adversity impacts negatively on mental health <sup>12</sup>. The psychological impact of the recent socioeconomic 'hostile environment' appeared in all survey responses and documents analysed.

Survey respondents emphasised **persistent mental health issues** for many people living with HIV.

*Service users still experience stigma relating to disclosure, and therefore become isolated, this also impacts on their wellbeing and mental health.* (Survey respondent).

However, surveys also described how **benefits changes worsened mental health**, leading to increases in and new instances of uncertainty, insecurity, depression and anxiety among service users.

*People are coming in destabilised by benefit changes and the disruption causes distress and often depression*  
(Survey respondent)

HIV organisations frequently described these service user experiences in terms of 'depression', 'stress', 'anxiety', 'suicide attempts', 'fear', and 'distress'. Their reports also linked this poor psychological health to the **socioeconomic effects of the benefits 'hostile environment'**:

*One of my patients became so very afraid of being assessed that he was very socially avoidant, totally depressed and spent most of his time in bed thinking of ending his life.* (HIV Scotland and Hepatitis Scotland, 2014, p28).

*The change from DLA to PIP which I will get a review regarding in 2015 has meant I am constantly worrying, I cannot support myself without this benefit and knowing how difficult they have made the new rules it's a constant worry.* (Counterpoint, 2014, p8).

Organisations reported some service users struggling with **feelings of shame** resulting from HIV stigma, but also from disparaging discourses around benefits and disability.

*I feel terrible shame at having HIV and even more shame at not being able to cope very well [...] I have become very aware of how people's attitudes have changed towards people on benefit I have felt people's prejudice and at times felt discriminated against.*



(Counterpoint, 2014, p5).

Survey respondents and reports also commented on themselves **needing to provide additional psychological support** as a result of health and care service cuts.

*Following cuts to other health and support services (especially mental health) we have seen a greater demand from clients with mental health needs.* (Survey respondent).

*Mental Health services seem to be particularly squeezed in West London. Referrals take a long time to turn around.* (Counterpoint 2014, p6).

Moreover, **austerity's specific impact on particular groups** –Black and minority ethnic communities, women, parents, and those coping with poverty, ageing, immigration, and complex psychological needs – whose mental health needs have increased, were noted.

*Stress levels are really high among some groups especially (Black and minority ethnic), women; high levels of anxiety, and many people report being on anti-depressants.* (Survey respondent).



Shan Kelley, *Bloody Positive*, 2016. Image used by kind permission of Shan Kelley, <https://shankelley.com/>

# 8. The HIV sector: Austerity effects and responses

*The entire loss of funding in 2010 was a major blow. We were expected to close, however the dedication of our staff and volunteers means that we are still here, still without regular funding however!*  
(Survey respondent).

*It is good to be able to report that Sahir House is still improving in terms of quality and range of services, despite it being another very challenging year for the sector, as cuts to statutory funding continue. [...] As nationally funding cuts have started to affect the voluntary sector, our challenge has been to continue to provide increased services in a changing climate – this has meant that some services such as therapies may be decreased in the coming year as funders and commissioners are also renegotiating contracts as they face their own future changes.*  
(Sahir House, 2011-2012, p.s 5, 7).

Survey responses and reports described how organisations faced **escalating work, year on year funding reductions and uncertainty in funding, and the domino effects of cuts elsewhere.**

*As we mentioned, in conducting the survey, we received a number of emails indicating that **smaller organisations had closed**. Survey responses and documents frequently referred to such closures:*

*Interview with J: I started to go to the day centre for people with HIV. They were really, really good but they*

*have all closed now.* (Eddystone Trust, 2018).

*Key issue: more and more services are closing down due to cutbacks... We are moving toward all drugs and alcohol [services] which do not cover the HIV sector or the long term older clients.* (Survey respondent).

Within austerity's hostile environment, **organisations were devoting considerable resources to finding new strategies.**

Some organisations downsized to volunteer operations. Elsewhere, the Counterpoint Alliance reported in 2010 that most organisations surveyed were significantly affected by reduced funding. Planned responses included reducing management and administrative staff (48%), reducing other staff (41%), restructuring (41%), collaboration (48%), reducing services (26%), and merging (7%).

In 2014, (ps 4, 8) George House responses included expanded volunteering, building medical liaisons, and strengthening service user access pathways. Over this audit's timespan, data indicated some organisations had indeed merged to pool dwindling resources. Others were collaborating, as with Salamander Trust's Mentor Mothers project for HIV positive pregnant women, operating across eight UK organisations, Kenya, and Uganda. Some organisations broadened focus, to address, like KwaAfrica (2018), health and wellbeing issues and gender issues like Female Genital Mutilation, and/or had specific regional or demographic targets, like Metro's specialist support in European languages. Some were developing imaginative new projects, like



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<https://www.facebook.com/PADHIV/>

Naz's joyful Noise cross-faith people with HIVs' choir.

Organisations were thus finding **ways to continue old but also provide valuable new services**. New provision also included more services around benefits and work, for instance Rain Trust's (2017) programme for HIV positive African-origin unemployed people; services previously statutorily covered, like the Brigstowe Project's (2017, p2) support with housing, immigration and training; expanded mental health provision, and

better services for children with and/or affected by HIV:

*CHIVA (Children's HIV Association) has developed a range of social interventions which address key impacts of HIV on children and their families; reducing social isolation; improving awareness and understanding of HIV; challenging and addressing impacts of stigma and discrimination and supporting the emotional effects of growing up with HIV.*

(Children's HIV Association, 2016, p2).

**Continuing high levels of effectiveness** were reported.

For instance, 92% of Body and Soul members using casework support said it made them less stressed. (2014, ps10-11). National AIDS Trust research on Personal Independence Payment work emphasised its positive outcomes:

*Case study 2: HIV support worker based in London whose client was awarded enhanced rate mobility: The outcome has had a positive effect on the client as he is now able to claim a taxi card. He is also able to use the money to attend more social activities which is resulting in a positive impact to his mental wellbeing. (NAT, 2017b, p16).*

However, across all data and the whole timespan, we noted **warnings of services reaching breaking point**.

The message is clear: **The sustained cuts in funding and services have had a detrimental effect on the psychosocial wellbeing of many people with HIV.**

The headline medical story of HIV is a good one. There is improved medical treatment, and new HIV diagnoses in the UK are declining. However, our survey results and document analysis suggest that the complex needs of many people with HIV are being inadequately addressed, as services are increasingly reduced and mainstreamed.

Public Health England recognizes the complex needs that now require continued attention, particularly for an aging HIV population:

*As people with HIV continue to age, it is critical that HIV and other services continue to evolve to meet the needs of people living with HIV including the management of comorbidities and other complex health conditions* <sup>13</sup>.

However, the emphasis of Public Health England is on infection and transmission and physical health. The psychosocial needs of people with HIV are being neglected, with significant detrimental impact.

In 2017-2018, the UK saw the largest increase in poverty since the 1980s <sup>14</sup>. The impact of austerity on mental health is now well-known <sup>15</sup>. Many HIV organisations report that HIV seems like a forgotten or 'left-behind' issue. In addition, stigma remains a significant problem, and the specific social and psychological needs of

people with HIV have been increasingly neglected, resulting in limited resources for living well.

Alongside austerity and cuts to services generally, the demands placed on HIV organizations to meet the needs of people with HIV have increased, while their own funding has decreased. Organisations are forced to find alternative ways to meet these demands, but their resources and services are at breaking point. Echoing the National AIDS Trust and HIV Scotland, as well as many of our survey respondents, we call for the integration of health and social services so that care for people with HIV can be combined and tailored to meet their specific needs, and for appropriate levels of funding to meet the challenges of the contemporary HIV epidemic in the UK. Without these initiatives, we will increasingly jeopardise the great promise of contemporary advances in the epidemic

*It is time for a system which prevents poverty, treats people with dignity and respect and supports everyone to flourish*

(HIV Scotland and Hepatitis Scotland, 2014, p10).



*As with many areas of public health short term cost cutting leads to more serious issues further down the line. Continued paring back of funding for HIV organisations risks undoing the progress made over the last decades. HIV is by no means over and the disjointed and underfunded services left after the 2012 health and social care reforms are struggling and reducing services at a time when they need to do the exact opposite.*

(Survey respondent)



Shan Kelley, *Tangles*, 2017. Image used by kind permission of Shan Kelley,  
<https://shankelley.com/>

# Acknowledgements

This report was researched and written by Chibuzo Aduaka, Tomas Campbell, Paul Clift, Kathryn Forbes, Lynda Gilby, Priyanka Goel, Cheryl Gowar, Rose Irtwange-Shikaru, Austine Karibo, Guillermo Llorca, Vevena McLeish, Sanny Mulubale, Sara Papparini, Mel Rattue, Poul Rohleder, Corinne Squire, Wezi Thamm and Alice Welbourne. Other Network members and organisations contributed as survey disseminators and contributors of documents for analysis; many thanks to them, also.

Network organisations kindly hosting meetings have included Metro, National AIDS Trust, Naz Project, Positive East, Positively UK, and River House. We are extremely grateful to our prior and current Network Administrators, Charlotte Smith and Sanny Mulubale.

Thanks go to Kathryn Forbes, Shan Kelley, Guillermo Llorca, Sanny Mulubale, Positively Mindful CIC and Mel Rattue for their kind permission for us to include their images. We would like to extend special thanks to Shan Kelley for his permission to use a number of his images.

Much appreciation goes to our excellent UEL design team, Hannah Coles, Patrick Mayhew, and Sneha Modhvadiya, with Dan Duran, for their inspiring work on the report.

We also want to thank other members of the 'Living with HIV' module group, 2017-2018, at UEL, not mentioned above, for their work; and UEL for its Civic Engagement and intern funding, which has helped

support the Network administratively and to generate this report.

Finally and most importantly, we would like to thank all HIV Psychosocial Network organisations and individual members, and survey responders for all aspects of their work on this report and their interest, dedication and support.'

<sup>1</sup> UNAIDS (2017). Ending AIDS: Progress towards the 90-90-90 targets. Geneva: UNAIDS.

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<sup>3</sup> For a general account of the issues discussed in this section, see Public Health England (2017a) and Public Health England (2017b), and NHS England (2018a). For detail on current treatment guidelines, see NHS England (2018b) and on treatment effectiveness, O'Connor and colleagues (2017). For 'U=U' endorsement in the UK, see BHIVA (2017). For medical experiences, see Public Health England (2015). For support and wellbeing, see for instance Positively UK (2018).

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<sup>4</sup> Three important recent studies of service cuts are Dalton (2016), and National AIDS Trust (2017a and b) which reports a 28% decrease in local authority HIV support services and a 12% decrease in primary HIV prevention and testing spend between 2015/2016 and 2016/2017. An example of studies of the effects for

specific service users is Stephenson and colleagues' study of older women (2017). The Kings' Fund (2017) has provided a comprehensive overview of the structure and future requirements of HIV services, given contemporary financial pressures, and emphasising also the importance of 'social, psychological and emotional wellbeing' for people with HIV who were among their informants. Finally, a telling forerunner of this work is the Sigma study of social care, support and information around HIV (Weatherburn et al., 2007) which reports many similar issues around complex needs, problematic reorganisations, and cuts not necessarily covered by new services.

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<sup>6</sup> UEL undergraduates taking a final year HIV course also contributed to data coding.

<sup>7</sup> See Braun and Clarke (2013) for thematic analytic procedures.

In what follows, we do not provide information about specific survey responders in order to protect their anonymity within a small sample and field. However,

we indicate the authors, dates and page numbers where appropriate, as well as document number, for the publically available document sample.

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<sup>8</sup> Another limitation of the research is that it is a small and not fully inclusive project. There are differences between the two data sources, also. The anonymous survey generated more intense responses than those of organisational reports written for specific audiences. The reports were more thematically comprehensive than the more selective, participant-framed survey responses. We decided to work with this combination of data types, in preference to generating a survey of a fuller, more standardised, but more demanding and researcher-focused kind.

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# Appendix 1. HIV Psychosocial Network Survey, 2017

## Survey respondents

Completion Rate: 64% (25). Complete: 16; partial: 9

1. What is the scope of your organisation?

National: 26.3% (5); Regional (county): 42.1% (8); Local (city): 31.6% (6)

2. Where is your organisation based?

England- London: 63.2% (12); England- Outside of London: 36.8% (7)

3. What are the client group(s) that your organisation is a provider for (e.g. MSM, young people, women, African community)?

a) All people living with HIV: 7

b) All people living with and affected by HIV: 3

c) All people living with and affected by HIV and poor sexual health: 1 see also b)

d) Older people; long term diagnosed; MSM; women; African community; heterosexual; trans community: 1 see also a)

e) MSM, women living with HIV, African community, sero-discordant couples: 1 see also b)

f) MSM, women, African: 1 see also a)

g) Older people, long-term diagnosed, African community: 1 see also a)

h) People living with HIV, mainly long-term diagnosed: 1 see also a)

i) BAME, families: 1 (specific groups)

j) African community: 1 (specific groups)

k) People living with HIV within specific boroughs in London, especially gay men and long-term survivors: 1 (specific groups)

4. How many service users or members you support annually?

Under 1000: 73.7% (14); 1000 and 10,000: 15.8% (3) Over 10,000: 10.5% (2)

5. How long have you been working at this organisation?

More than 1 year but less than 3 years: 21.1% (4)

3 to 6 years: 5.3% (1)

More than 6 years but less than 9 years: 21.1% (4)

9 years or more: 52.6% (10)

6. How long have you been working on HIV issues/in the HIV sector?

More than 1 year but less than 3: 15.8% (3)

3 to 6 years: 5.3% (1)

More than 6 years but less than 9 years: 10.5% (2)

9 years or more: 68.4% (13)

7. What position do you primarily identify with?

HIV service provider: 78.9% (15); Expert by experience: 10.5% (2)

Other: 10.5% (2) CEO (1); HIV peer support services (1)

Survey questions

8. From your experience of working with people living with HIV, have you noticed any changes in social, psychological and health circumstances for your service users since 2010?

8a. Social changes (n = 17)

8b. psychological changes (n =16):

8c. health changes (n = 15)

9. From your experience working at an HIV community organisation, what have some of the key challenges been for the organisation since 2010? (n=16)

10. From your experience working in an HIV community organisation what do you feel are the current key issues and concerns with regards to people living with HIV in the UK? (n=16)

11. Anything else you would like to add? (n=2)

# Appendix 2.

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